

To: SofS and PS(PC)

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LONG COVID – WEEKLY UPDATE

DATA DASHBOARD (Annex A)

As per the previous update note, we have attached the dashboard which includes data from studies such as ONS, activity data from NHSEI, press reports, social media and the relevant research.

Update from Roundtable last week on 23 September

Patient representatives valued the opportunity to put forward their experiences. We are anticipating the next roundtable being clinically focused.

Clinical trial follow-up

One of the points raised during the session related to 'red tape' and impact on the clinical trial arm of one of the research studies (STIMULATE ICP^[1]). Ondine Sherwood, Long COVID SOS has followed-up with additional information which has been shared with the relevant officials in the Science Research and Evidence Directorate and the team has subsequently written to the CMO.

To ensure the candidate drugs included in this study were appropriate for the treatment of non-hospitalised patients, the research commissioning panel suggested that advice should be sought from the COVID Therapeutics Advisory Panel (C-TAP). C-TAP has met and discussed the proposed drugs but did not consider there was enough evidence to support the use of any of the candidate drugs put forward (in part, due to the poor understanding at present of the biological mechanism underlying Long COVID symptoms). This has led to the research team having to pause its set up of the trial.

It has now been agreed that further expert advice should be sought as, a number of different classes of pharmacological therapeutics are currently being prescribed by Long COVID clinics and GPs. It is proposed that experts from a range of disciplines

^[1] The STIMULATE-ICP project has been funded to look at existing drugs to treat long COVID and measure effects with regards to symptoms, mental health and outcomes such as returning to work. It will also assess the use of MRI scans to help diagnose potential organ damage as well as offering enhanced rehabilitation through joined-up specialist care.

including Long COVID clinicians will be asked to consider whether trialling some of the drugs that are being routinely prescribed to people with Long COVID in the STIMULATE-ICP would be a good approach.

It is also proposed that this process should be further informed by preliminary findings on the mechanisms of the disease that are emerging from Long COVID research. The minor delay caused whilst this further advice and evidence is sought will be balanced out by having the assurance that there is a clear rationale for the choice of drugs being tested in this study.

CMO and CSA are being asked to consider this new proposal to help identify which pharmacological therapeutics should be chosen as candidates for this trial. The STIMULATE-ICP team are being kept informed of this process so it is ready to proceed as soon as possible with this important trial.

WHO technical briefing on rehabilitation

Officials and counterparts from NHSEI attended a technical briefing on rehabilitation and COVID-19. The briefing used a number of examples from the UK (including pointing to the NICE guidelines, ONS prevalence data and NHS service models). The WHO session emphasised the importance of investing in rehabilitation services noted the challenges that many countries had faced in retaining rehabilitation capacity during the pandemic (the WHO estimated that 75% of countries last year reported partial/severe/complete disruption to rehabilitation services during COVID-19). Rehabilitation capacity has been an issue raised during a number of Long COVID roundtables and NHSEI's National Taskforce has a workstream focused on rehabilitation. Rehabilitation may be a topic of interest for a future ministerial roundtable.

Scotland Long COVID publication

On 30 September the Scottish Government published a paper drawing together the various workstreams and commitments relating to Long COVID. The publication focuses on what members of the public can expect from the health service as well as commitments from the Scottish Government (largely focused on supporting NHS Boards).

Notable press reports

Comparison to influenza

There was widespread media coverage of a study from the University of Oxford and the National Institute for Health Research (NIHR) Oxford Health Biomedical Research Centre. The research used data from electronic health records of 273,618 patients diagnosed with COVID-19 and estimated the risk of having long COVID features in the 6 months after a diagnosis of COVID-19. It compared the risk of long COVID features in different groups within the population and also compared the risk to that after influenza. The research found that over 1 in 3 patients had one or more features of long-COVID recorded between 3 and 6 months after a diagnosis of COVID-19. This was significantly higher than after influenza. The risk of long COVID features was

higher in patients who had more severe COVID-19 illness, and slightly higher among females and young adults. White and non-white patients were equally affected.

Schools infection survey

There was also coverage of publication of the Schools Infection Survey and findings relating to Long COVID. Among survey respondents experiencing ongoing symptoms at four weeks post-infection, 90% of staff members reported their ability to carry out activities at work reduced only a little or not at all, while half of pupils reported that they attended school as normal despite symptoms.

Vitamin A

There was also coverage of a trial relating to Government backed NIHR research which is aiming to see if Vitamin A delivered via nasal drops can help people who have had their sense of smell altered by COVID-19.